

# 2010 Asian Chinese Quality of Life Conference

## Choosing the Right Health-related Quality of Life (HRQOL) Measure

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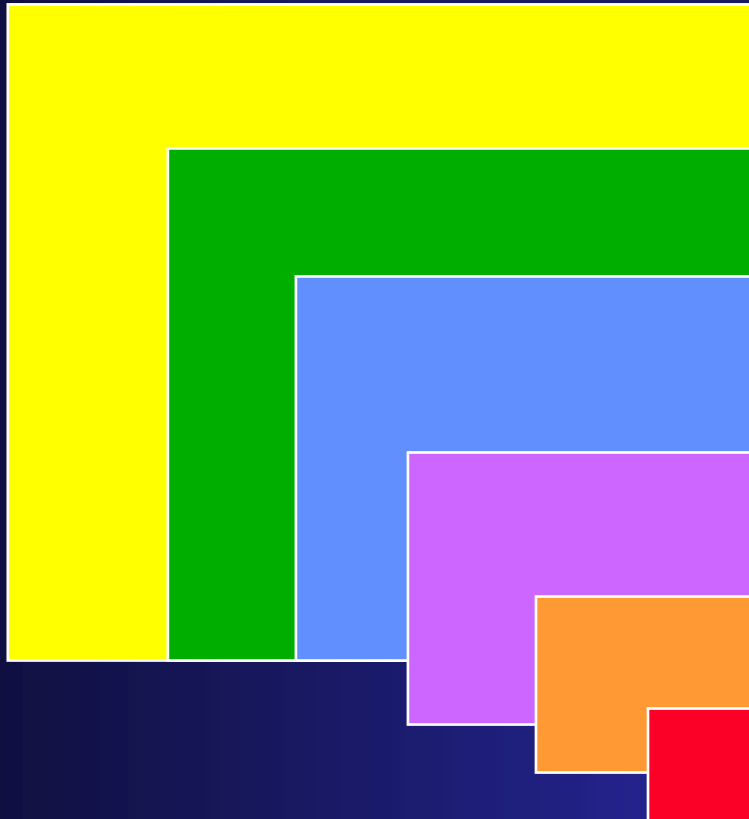


# Choosing the Right HRQOL Measure

- Applications of HRQOL measures
- Types of HRQOL measures
- Selection Criteria of HRQOL measures
- Translation of HRQOL measures



# Health Outcomes



- Patient Reported Outcomes
- Quality of life
- **HRQOL**
- Health status
- Morbidity (diseases, illness, disability)
- Mortality/survival

# Relevance of HRQOL Outcomes

- Incurable diseases, e.g. cancer, AIDS
- Chronic diseases, e.g. asthma, arthritis
- Disabling diseases, e.g. stroke, CHD
- Psychological illnesses, e.g. depression
- Functional disorders, e.g. dyspepsia  
impotence
- Cost-effectiveness analysis



# Purposes of HRQOL Assessment

- **Evaluative**
  - Impact of illness
  - Effects of treatment
  - Quality of care
- **Discriminative**
  - Population groups
  - Severity of illness
- **Predictive Outcome**
  - Screening tool
  - Service utilization
  - Mortality
- **Cost-effectiveness**
  - Quality adjusted life years (QALYs)



工欲善其事，  
必先利其器

**A good instrument is the  
pre-requisite of success**



# Purpose of HRQOL Measures

- **Generic**
  - Ambulatory/hospitalized/adults/children
- **Disease Specific**
  - disease group/individual disease
  - Modular (generic + disease specific)
- **Utility**
  - Preference-based measure of health

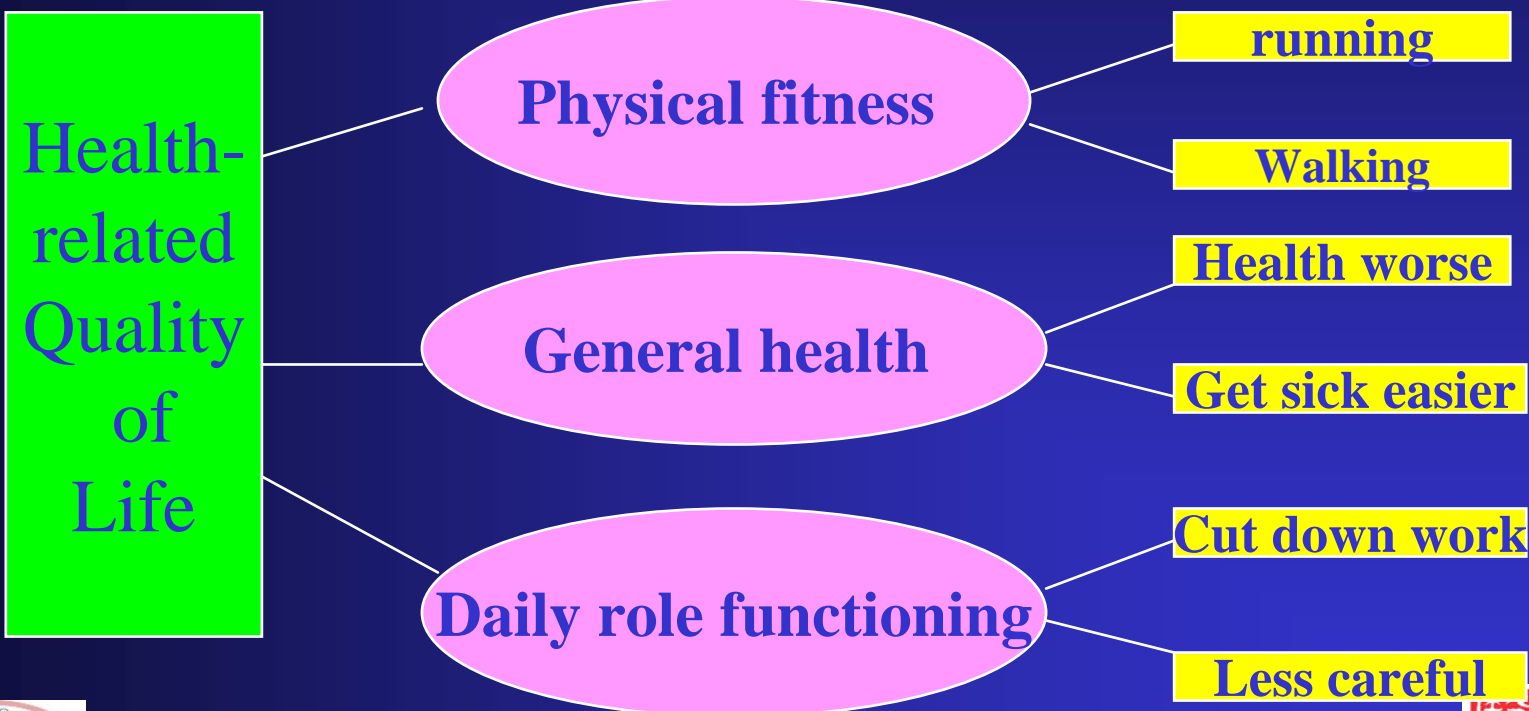


# Conceptualization of HRQOL Measures

**Latent  
Variable**

**Dimension/Domain  
(Scale)**

**Indicator  
(Item)**





# HRQOL Domains

*Wilson et al. JAMA 1995; 273:59-65*

## Essential

- Subjective
- Functioning- physical, daily role, social
- Mental (emotional) health status
- General health perception

## Important

- Vitality
- Symptoms, e.g. pain



# Generic HRQOL Measures

## SF-36 Health Survey

- Physical Functioning
- Role – physical
- Bodily pain
- General health
- Vitality
- Social functioning
- Role-emotional
- Mental health



## WHO-QOL-BREF (HK)

- Overall QOL
- Physical health (pain, energy, sleep, mobility, ADL, work,)
- Psychological (feeling, cognition, self-esteem, eating, spirituality)
- Social (support, sex)
- Environment (safety, home, finance, access to care, leisure, pollution)



# Disease Specific HRQOL Measures

## FACT-C (CRC)

- **FACT-G scales**
  - Physical well-being
  - Social well-being
  - Emotional well-being
  - Functional well-being
- **Colorectal cancer scales**
  - Abdominal pain, weight, bowel control, digestion, diarrhoea, appetite, self-image, stoma problems



## EORTC – CRC specific

- **EORTC QLQ-C30 scales**
  - 6 Functional (incl. cognitive & general health status)
  - 9 Symptoms scales (dyspnoea, pain, fatigue, insomnia, appetite, nausea, constipation, diarrhoea, finance)
- **EORTC QLQ-CR38**
  - 4 functional scales ( image, future, & 2 on sex)
  - 7 symptom scales (urination, chemo S/E , GI, sex, defecation, stoma, wt)



# Health Preference (Utility) Measures

- SF-6D

- Physical functioning(6)
- Role limitation (4)
- Pain (6)
- Vitality (5)
- Social functioning (5)
- Mental Health (5)

- EQ-5D

- Mobility (3)
- Self-care (3)
- Usual activities (3)
- Pain (3)
- Anxiety/depression (3)

- HUI-3

- Vision (6)
- Hearing (6)
- Speech (5)
- Ambulation (6)
- Dexterity (6)
- Emotion (5)
- Cognition (6)
- Pain (5)



# Scoring HRQOL Measures

- **Response Choices**

- Dichotomous
- Likert scale
- Visual analogue scales

- **Scoring algorithm**

- Equal/ weighted summation
- Profile (continuous/ categorical)
- Summary/ overall
- Preference (utility) index
- Norm-based scoring



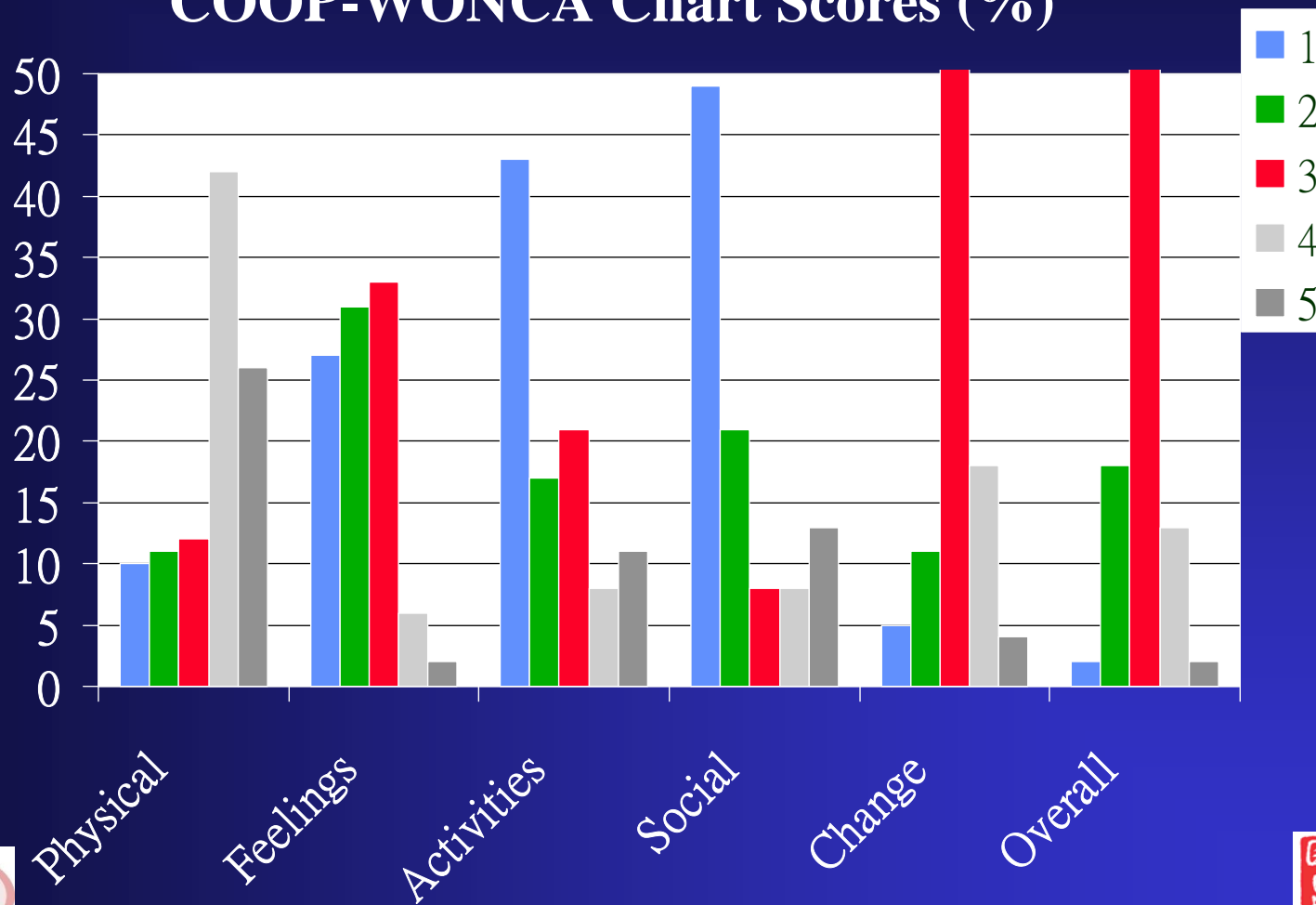
# The COOP/WONCA Charts

- **Six single-item charts (domains)**
  - physical fitness
  - feelings
  - daily activities
  - social activities
  - change in health
  - overall health
- **5-point Likert scales**
  - No difficulty
  - A little
  - Some
  - Much
  - Extreme
- **One categorical score for each domain, higher score = worse**



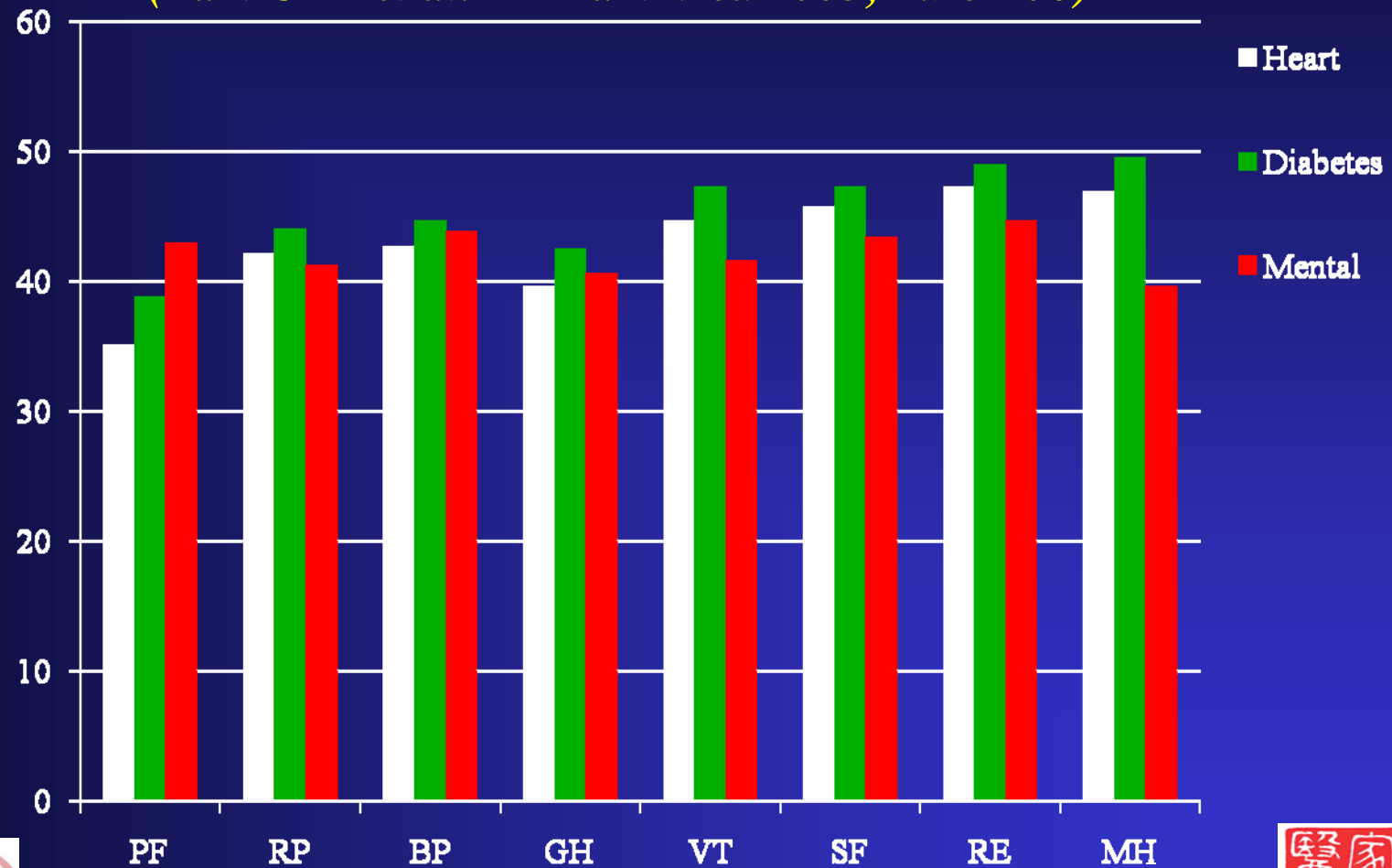
# HRQOL of Stroke Patients

COOP-WONCA Chart Scores (%)



# HRQOL Profile Scores

*(Lam CLK et al. AP Fam Med 2003; 2:98-106)*



HK Chinese Norm-based SF-36 Scores





# Health Preference (Utility) Score

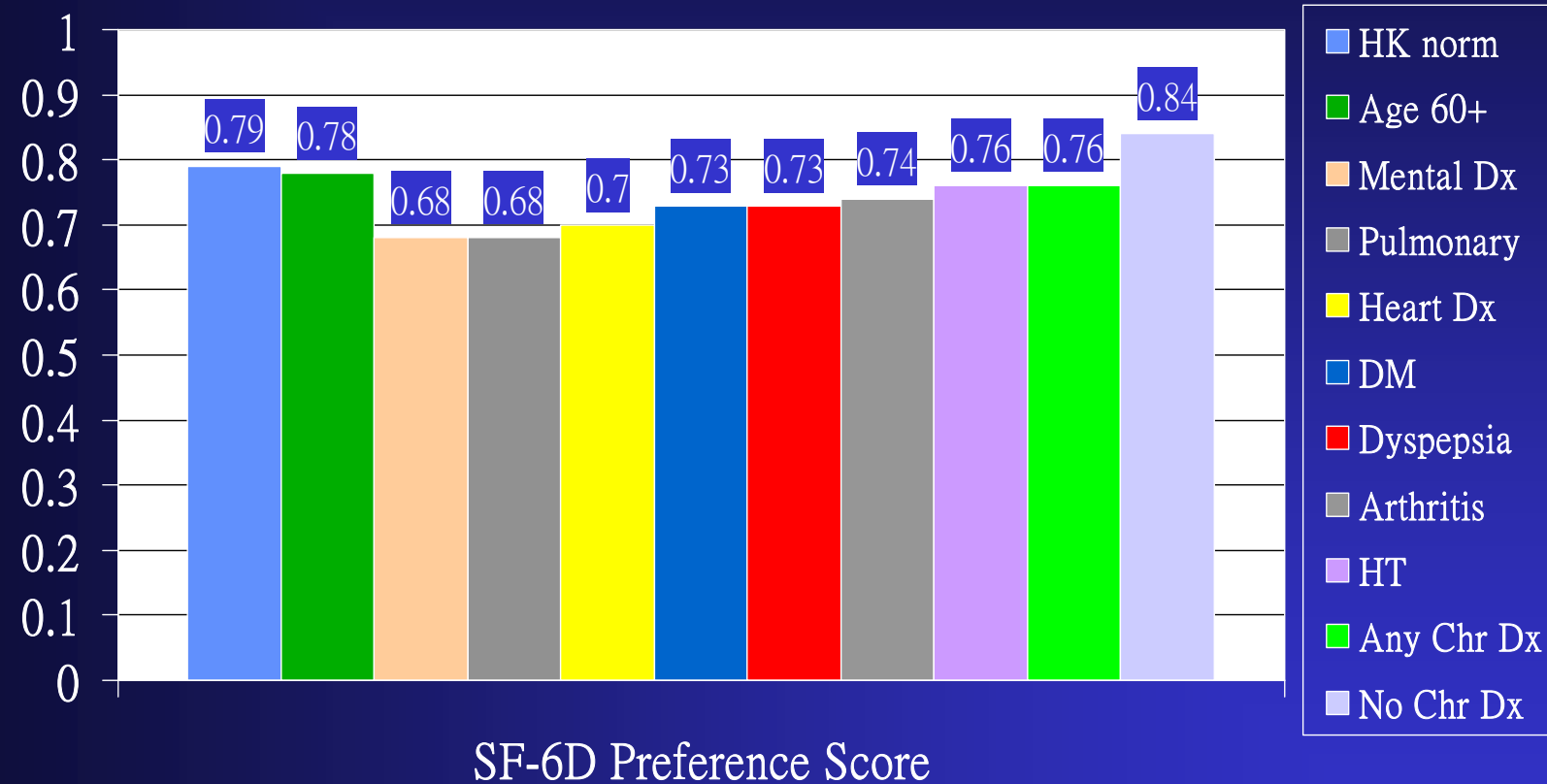
- PF Your health limits you a little in vigorous activities ( level 2) = - 0.05
- RL You accomplish less than you would like (level 3) = - 0.035
- SF Your health limits your social activities none of the time (level 1) = 0
- Pain You have pain that interferes with your normal work a little (level 3) = -0.037
- MH You feel tense or downhearted and low a little of the time (level 2) = -0.038
- VT You have a lot of energy some of the time (level 3) = -0.056

$$\text{SF-6D score} = 1 - 0.050 - 0.035 - 0 - 0.037 - 0.038 - 0.056 = 0.784$$



# Health Preference of HK Population

*Lam et al, 1998 (N=2410)*



# Selection Criteria of HRQOL Measures

- **Conceptualization**
  - Fit for purpose
  - Suitable population
  - Appropriate domains
- **Operation**
  - Language
  - Respondent burden
  - Administration method
  - Recall time frame
  - Scoring algorithm
- **Psychometric properties**
  - Validity
  - Reliability
  - Sensitivity
  - Responsiveness
  - Interpretation
- **Administration**
  - Copyright
  - Loyalty



# Validity of HRQOL Measures

- **Face**
  - Expert & lay evaluation
- **Content**
  - Relevant, important, representative
- **Construct (conceptual)**
  - Scaling & factor structure
  - Concurrent
  - Correlations with external criteria
- **Criterion**
  - gold standard



# Reliability

<b>SF-36 (n=2410)</b>	<b>Cronhach' s alpha</b>	<b>Test-retest difference</b>	<b>Intraclass correlation</b>	<b>Reliaibility coefficient</b>
<b>PF</b>	<b>0.81</b>	<b>0.66</b>	<b>0.91</b>	<b>0.81</b>
<b>RP</b>	<b>0.83</b>	<b>5.54**</b>	<b>0.79</b>	<b>0.41</b>
<b>BP</b>	<b>0.74</b>	<b>2.30</b>	<b>0.73</b>	<b>0.41</b>
<b>GH</b>	<b>0.65</b>	<b>-0.90</b>	<b>0.88</b>	<b>0.83</b>
<b>VT</b>	<b>0.72</b>	<b>1.13</b>	<b>0.83</b>	<b>0.65</b>
<b>SF</b>	<b>0.75</b>	<b>2.03*</b>	<b>0.73</b>	<b>0.49</b>
<b>RE</b>	<b>0.82</b>	<b>-1.97</b>	<b>0.77</b>	<b>0.33</b>
<b>MH</b>	<b>0.78</b>	<b>1.02</b>	<b>0.68</b>	<b>0.38</b>

## Sensitivity to Group Differences

Chronic Dx	SF-36 PCS	Effect size	SF-36 MCS	Effect size
None	55.12	-----	47.82	-----
DM	45.50*	1.32	47.84 <sup>#</sup>	0.002
Heart	43.70*	1.56	45.83*	0.21
Mental	47.78	1.00	39.14*	0.9

\*  $p < 0.01$ ; #  $p > 0.05$



# Responsiveness to Change with Treatment

(Lam CLK & HU W, Quality of Life Research 2002; 11: 668.)

<i>Mean Change in Scores</i>	SF36 PCS (0-100)	SF36 MCS (0-100)	SF-6D preference (0-1)	symptom (12-60)
OGD (n=83)	2.42 <sup>^</sup>	1.48	0.029 <sup>^</sup>	-5.13 <sup>^</sup>
HP test & treat (n=74)	2.79 <sup>^</sup>	3.94 <sup>^*</sup>	0.063 <sup>^*</sup>	-5.21 <sup>^</sup>
Cisapride (n=72)	2.92 <sup>^</sup>	0.13 <sup>*</sup>	0.026 <sup>^*</sup>	-4.08 <sup>^</sup>

<sup>^</sup> Significant difference between baseline & wk 6 scores by paired *t* test  $p < 0.05$

<sup>\*</sup> Significant difference between groups by 2-sample *t* tests  $p < 0.05$



# Translation of QOL Measures

ISPOR Task Force for Translation and Cultural Adaptation. *VIH* 2005; 8:94-104

- Forward translation (double)
- Reconciliation among expert & translators
- Back translation: semantic equivalence
- Harmonization (multiple translations)
- Cognitive debriefing (5 to 10 subjects)
- Review of cognitive debriefing results
- Final revision
- Proof-reading





# Semantic Equivalence

..... Were limited in the kind of work or other activities

- 工作或從事某些活動受到限制

BT: doing **some kind of** work or activities had limitations

- 工作或其它活動的種類受到限制

BT: work or other **activity kind** were limited



# Cognitive Debriefing

**I am as healthy as anyone I know**

- 您**和**所有您認識的人一樣健康 (BT: You and all the people you know are equally healthy)
  - I don't know whether other people are healthy or not!
- 您**好像**所有您認識的人一樣健康 (BT: You are similar to people you know in health)



# Choosing the Right HRQOL Measure

- ✓ Is HRQOL an appropriate outcome?
- ✓ Does the measure fit for the purpose of the HRQOL assessment?
- ✓ Are the data collected suitable for the analysis?
- ✓ Is the HRQOL measure feasible or valid for the target population and setting?



# Useful Resources

- International Society for Quality of Life (Asian Chinese Chapter) [www.isoqol.org](http://www.isoqol.org)
- HK Society for Quality of Life (HKSoQOL) [www.hksoqol.org](http://www.hksoqol.org)
- PROQOLID, MAPI Research Trust [www.proqolid.org](http://www.proqolid.org)
- Health Research Associates Inc. [www.hrainc.net](http://www.hrainc.net)
- Medical Outcomes Trust [www.outcomes-trust.org](http://www.outcomes-trust.org)
- QualityMetric Inc. [www.qualitymetric.com](http://www.qualitymetric.com)

